Institution: Lancaster University

Unit of Assessment: 3 Allied Health Professions, Dentistry, Nursing and Pharmacy

Title of case study: Developing the evidence base in palliative care: from mapping to international policy and practice change

1. **Summary of the impact** (110 words)

Research carried out in the International Observatory on End of Life Care (IOELC) at Lancaster University led by Professor Payne has played a major role in influencing the strategic direction of service and policy development globally. IOELC initiated the systematic collation of development data and delivered the first research-based international analysis of the development of palliative care. For example, research on access to opioids in 12 resource poor countries in central and eastern Europe via the ATOME project has delivered major impact, leading to significant changes in legislation and policy and improved access to pain medication, and palliative and end of life care for millions of people around the world.

2. Underpinning research (466 words)

Palliative care is an emerging multidisciplinary health and social care practice and research discipline concerned with improving the quality of life for people with advanced life-threatening conditions, irrespective of the specific disease. It aims to ensure excellent symptom management, psychological, social and spiritual care. Estimates indicate that 60% of dying people could benefit from palliative care. The mapping of global development in palliative care provision was initiated in 2003 upon the establishment of the IOELC at Lancaster University. The work has been undertaken by Professor Sheila Payne (Professor of Palliative Care 2006-present) Professor David Clark (Professor of Medical Sociology 2003-9); Dr Michael Wright (Senior Research Fellow 2003-10) and Dr Thomas Lynch (Research Associate 2010-present).

This work pioneered the use of graphic global and regional maps and 'country reports' which have helped to make the case for palliative care to funders and governments, and to highlight areas where experience and skills could be shared. The focus of the initial research was to understand the range of organisational models of care being used worldwide, and how they are delivered in different countries, health and economic systems, and different environments of care (home, hospital, hospice, and care home). Improving access to adequate pain control, symptom relief and psychosocial support to patients, and support to families, is a major global public health challenge.

To date 67 country reports have been produced, which are freely available on the IOELC website (http://www.lancs.ac.uk/shm/research/ioelc/international/reports.php). Significant research achievements include development of the first methods for mapping palliative care development at the country level, using a combination of epidemiological, demographic and ethnographic methods (Ref 3.1; 3.2). Subsequently a revised global mapping of palliative care development was commissioned by the World Wide Palliative Care Alliance using the new typology (3.3), with a further revision in autumn 2013. This work has resulted in some major monographs as well as papers in peer reviewed journals and critical reviews of international comparative analysis in end of life care (3.4, linked to Project 2, EURO IMPACT).

Building on the mapping work, the key contribution by IOELC has been to work at the interface between international comparative analysis and policy development, in close collaboration with the World Health Organisation. The 'Access to Opioid Medication in Europe' (Project 1, ATOME) project funded under the EC Framework 7 programme for five years (2009-2014) is one such project and provides an exemplar for this approach. Using Delphi and expert consensus methods, we updated the WHO policy guidelines (3.6) on controlled medications based on the principle of balance; recognising that countries need to regulate opioids to prevent illicit drug use and criminal activity, while also enabling patients with advanced diseases such as cancer, to have access to

affordable pain relief. Further research includes identifying and evaluating models of integrated palliative care in Europe (Project 3, InSupC).

3. References to the research

3.1 Clark, D. Wright, M. Hunt, J. and Lynch, T. 2007. Hospice and Palliative Care Development in Africa: A Multi-method Review of Services and Experiences. *Journal of Pain and Symptom Management* 33: 698-710. doi:10.1016/j.jpainsymman.2006.09.033

3.2 Wright, M. C., Clark, D., Wood, J. and Lynch, T. 2008. Mapping levels of palliative care development. *Journal of Pain and Symptom Management* 35: 469-485. doi:10.1016/j.jpainsymman.2007.06.006

3.3 Lynch, T., Connor, S. and Clark, D. 2013. Mapping levels of palliative care development: a global update. *Journal of Pain and Symptom Management* 45:1094-1106. doi:10.1016/j.jpainsymman.2012.05.011

3.4 Loucka M, Payne S, Brearley S How to measure the international development of palliative care? 2013. A critique and discussion of current approaches *Journal of Pain and Symptom Management* doi:10.1016/j.jpainsymman.2013.02.013

3.5 Lynch, T., Clark, D., Centeno, C., Rocafort, J., Flores, L. A. Greenwood, A., Praill, D., Brasch, S., Giordano, A., De Lima, L., and Wright, M. 2009. Barriers to the development of palliative care in CEE and CIS. *Journal of Pain and Symptom Management*, 37(3): 305-315. doi:10.1016/j.jpainsymman.2008.03.011

3.6. Jünger, S., Brearley, S., Payne, S., Mantel-Teeuwisse, A.K., Lynch, T., Scholten, W., Radbruch, L. Consensus building on access to controlled medicines: a four-stage Delphi consensus procedure. *Journal of Pain and Symptom Management.* 2013 May 21. pii: S0885-3924(13)00192-9. doi: 10.1016/j.jpainsymman.2013.01.014.

Selective competitive research support

Original research projects to perform significant and rigorous mapping studies in key world regions, were undertaken with various funders, including: in Africa (Diana, Princess of Wales Memorial Fund) 2004; in India (Irish Hospice Foundation, National Hospice and Palliative Care Organisation (USA) 2005); in the Middle East (National Cancer Institutes (USA)); in South East Asia (Open Society Institute (USA) 2006), paediatric palliative care in Europe (Maruzza Foundation (Italy) 2012); and globally mapping palliative care postgraduate education programmes (Open Society Foundation (USA) - 2012).

Total value since 2009: **£9.3 million**

European Commission Framework Programme 7 projects:

1. ATOME Access to Opioid Medication in Europe http://www.atome-project.eu/ funded 2009-2014 led by Lukas Radbruch (Germany), Willem Scholten (WHO) and Sheila Payne (Lancaster UK) which aims to increase access to opioid in 12 resource poor countries in Central and Eastern Europe by working with national governments and national associations; the IOELC are undertaking the research that underpins this project (www.atome.org.uk). The project also involves Tom Lynch and Saskia Junger (PhD student). Euros 2,449,688
2. EURO-IMPACT www.euro-impact.eu funded 2010-2014 led by Luc Deliens (Belgium), Sheila Payne (UK) et al. This consortium was awarded European Commission funding under Marie Curie Actions of Framework Programme 7. This project also involves Sarah Brearley and Martin Loucka (PhD student). Euros 3,985,789
3. InSup-C Patient centred pathways in advanced cancer and chronic disease www.insup-c.eu funded 2012-2016 led by Jeroen Hasselaar (The Netherlands), Sheila Payne (UK), Clive Ondari (WHO) et al Euros 2,911,593

4. Details of the impact (797 words)

This research undertaken at Lancaster University has played a major international role in influencing the strategic direction of service and policy development in end of life care. Our research has influenced funding bodies, policy makers and professional organisations in promoting the development and refinement of services, and therefore improving access to palliative care for a substantial number of people across the world. Below we provide four examples of the broad impacts we have delivered (4.1-4.4), together with one detailed example (4.5), of several available:

4.1 In Europe, the IOELC mapping of palliative care services was extensively drawn upon to inform the evidence base and recommendations in an independent report commissioned by the European Parliament Economic and Scientific Policy Department led by Martin-Moreno et al (5.1). This has influenced governments in the UK, Germany, Italy and elsewhere to introduce policy directives such as the first ever national End of Life Care Strategy in 2008 for England and Wales.

4.2 The European Association of Palliative Care (an International non-governmental organisation recognised by the Council of Europe) have a Task Force on Palliative Care Development in Europe (www.eapcnet.eu) which has published extensive and detailed maps of palliative care development in Europe (called an Atlas) with the support of IOELC, the latest update published in 2013 (5.2). The mapping methodologies have been drawn from the work of the IOELC, in turn leading to improvements in hospice and palliative care services.

4.3 A major influential international report (5.3) commissioned by the Lien Foundation in Singapore and carried out by the Economist Intelligence Unit (2010) once again drew upon IOELC research and consultation with IOELC researchers (Payne, Clark). This report produced a ranking of palliative care development in 40 countries of the world, and with a more complex set of indicators. This report provided benchmarks against which national governments, including the UK (ranked first), are able to measure palliative care service development.

4.4 Access to effective, affordable pain relief is an essential part of palliative care, but access is far from uniform (5.4): 10% of the world population consumes 90% of the available morphine. **This means that millions of people die in pain**. There are many barriers preventing access to opioids operating at different levels including: public fear of opioids; professional ignorance of pain assessment; reluctance to prescribe in sufficient doses in a timely way; restrictions on the storage and delivery of medications; and national legal and regulatory restrictions on opioid use because of fears about illicit drug use and criminal activity. In 2011, Human Rights Watch (5.5) documented pain and palliative care services in 40 countries citing IOELC research. In September 2011, at the UN High Level Summit on the prevention and control of Non Communicable Diseases (NCDs), the advocacy of international cancer and palliative care organisations drew extensively on data from IOELC sources and the early work of the ATOME project, to successfully achieve the inclusion of palliative care into the political declaration on the prevention of NCDs that was signed at the meeting and subsequently in 2013 the inclusion of a palliative care indicator.

4.5 In the ATOME project, 12 European countries where opioid consumption was below average in 2006 were identified and we prepared detailed 'Country Reports' compiling demographic, health care, medication utilisation and ethnographic information: **Bulgaria; Cyprus; Estonia; Greece; Hungary; Latvia; Lithuania; Poland; Serbia; Slovakia; Slovenia; Turkey.**

This project delivered policy revisions in access to opioid medication and training of practitioners in the 12 resource poor countries (3.5), working collaboratively with national governments, legal representatives, harm reduction agencies and national palliative care and oncology associations. The extensively revised policy document by the WHO "*Ensuring balance in national policies on*

controlled substances. Guidance for availability and accessibility of controlled medicines", is published free in 15 languages, has been distributed worldwide (5.6) and was co-ordinated by IOELC. Cumulatively, the ATOME project has resulted in an impetus to change opioid policy and legislation. For example, in Hungary the basic Decree defining prescription by physicians, dispensing by retail pharmacies, and the use, registration and storage by healthcare providers is Decree 43/2005 (X.15) EüM, issued by the Ministry of Health. Since 2011, this Decree has been amended twice; on both occasions it was simplified and this has facilitated the accessibility of opioids in the country. A new Decree (No. 22/2012 IX. 14) EMMI of the Minister of Human Resources on obtaining a specialist qualification in health, ensures that practising physicians must now undertake a minimum of 40 hours training in palliative care and pain management. The programme of training is published on the website of the Ministry of Human Resources (5.7, 5.8) following consultation with the relevant professional associations and Ministerial approval. The ATOME project has had a direct impact resulting in changes to prescribing, education and national drug strategy in Hungary (5.9).

5. Sources to corroborate the impact

5.1 Martin-Moreno J, Harris M, Gorgojo L, Clark D, Normand C, Centeno C. Palliative Care in the European Union. European Parliament Economic and Scientific Policy Department 2008. IP/A/ENVI/ST/2007-22. PE404.899 [Online] http://www.europarl.europa.eu/activities/committees/studies/download.do?file=21421

5.2 Centeno C, et al *EAPC Atlas of Palliative Care in Europe 2013 – Cartographic Edition*, European Association for Palliative Care Press, Milan, 2013

5.3 The Quality of Death: Ranking End of-life-Care Across the World, commissioned by the Lien Foundation, Singapore, published by the Economist Intelligence Unit, July 2010. http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf

5.4 Duthey B, Scholten W. Adequacy of opioid analgesic consumption at country, global, and regional levels in 2010, its relationship with development level, and changes compared with 2006. *Journal of Pain and Symptom Management*, published online 18th July 2013 doi.org/10.1016/j.jpainsymman.2013.03.015

5.5 Human Rights Watch Global State of Pain Treatment: http://www.hrw.org/reports/2011/06/01/global-state-pain-treatment-0

5.6 World Health Organization*. Ensuring balance in national policies on controlled substances. Guidance for availability and accessibility of controlled medicines.* Geneva: World Health Organization; 2011.

5.7 Hungarian Ministry of Human Resources (http://www.kormany.hu/download/4/26/b0000/szakorvosi%20alap%20szakk%C3%A9pz%C3%A9s.pdf)

5.8 Letter from Deputy Director, Institute of Behavioural Sciences, Semmelweis University, Hungary about the impact of the ATOME project

5.9 Letter from Professor in the Institute of Family Medicine, University of Pecs, Hungary on contribution of ATOME project to changes in accessibility and availability of opioids in Hungary